

# XII: INFORMATION DISSEMINATION



**AREA OF EMPHASIS:**

# Information Dissemination

## SCIENTIFIC ISSUES

Effective and efficient information dissemination and exchange are important tools in the effort to control and end the AIDS epidemic. The NIH has responsibility for disseminating information to support research, treatment, and prevention related to HIV and AIDS. Progress in these areas depends on the transfer of information to researchers, health care and service providers, HIV-infected individuals and their families, policymakers, and the public. These audiences have varying needs for information that is critical in the fight against HIV/AIDS. The changing demographics of the epidemic provide challenges to disseminating HIV research results to communities at risk in the United States, including women and minorities, as well as those at risk in developing countries. An additional challenge is providing information in formats that are useful to both health care providers and patients. The flow of information among researchers, health care providers, and the affected communities represents new opportunities to rapidly translate research into practice and to shape future research directions.

*A Guide to NIH HIV/AIDS Information Services* is updated annually and made available in both printed and electronic form through the National Library of Medicine (NLM) AIDS Web site (<http://aids.nlm.nih.gov>). This guide provides a comprehensive listing of NIH-supported information services that assist care and service providers, patients, and the public.

## **TREATMENT AND PREVENTION GUIDELINES**

Access to clinical care guidelines, standards of care, and results of state-of-the-art meetings is critical for physicians and patients. Treatment guidelines for the use of new and complex antiretroviral regimens are continually updated. The guidelines are available in print form and on the Internet Web site of AIDSinfo (<http://AIDSinfo.nih.gov>). Titles available include the following:

- *Guidelines for the Use of Antiretroviral Agents in HIV-Infected Adults and Adolescents*
- *Guidelines for the Use of Antiretroviral Agents in Pediatric HIV Infection*
- *Public Health Service Task Force Recommendations for Use of Antiretroviral Drugs in Pregnant HIV-1 Infected Women for Maternal Health and Interventions to Reduce Perinatal HIV-1 Transmission in the United States*
- *Updated U.S. Public Health Service Guidelines for the Management of Occupational Exposures to HBV, HCV, and HIV and Recommendations for Postexposure Prophylaxis*
- *Management of Possible Sexual, Injecting-Drug-Use, or Other Non-occupational Exposure to HIV, Including Considerations Related to Antiretroviral Therapy*
- *Guidelines for the Prevention of Opportunistic Infection in Persons Infected with HIV*
- *Updated Guidelines for the Use of Rifamycins for the Treatment of Tuberculosis Among HIV-Infected Patients Taking Protease Inhibitors or Nonnucleoside Reverse Transcriptase Inhibitors*
- *Revised Guidelines for Counseling, Testing, and Referral of Persons Living with HIV*

## **ELECTRONIC INFORMATION RESOURCES**

Computerized databases and other types of electronic resources are a vital component of NIH AIDS information dissemination, allowing global access to information concerning basic research, clinical trials availability and results, standards of care, and other information of interest to HIV-infected individuals, their care providers, and their advocates. Examples of these critical resources follow.

## NLM Databases

**Internet:** <http://pubmed.gov>

MEDLINE/PubMed is available free of charge to users worldwide. The AIDS subset of this database includes citations (with abstracts when available) to AIDS-related journal articles and newsletters. Abstracts from significant AIDS-related meetings and conferences, notably the International AIDS Conferences, are included in the Gateway (<http://gateway.nlm.nih.gov>), which also provides access to other NLM information resources. International, national, and State organizations involved in AIDS are found in DIRLINE (<http://dirline.nlm.nih.gov>).

## AIDSinfo

**Internet:** <http://AIDSinfo.nih.gov/>

**Phone:** 1-800-HIV-0440 (1-800-448-0440)

**Fax:** 1-301-519-6616

**Outside U.S.:** 1-301-519-0459

**TTY:** 1-888-480-3739

Monday to Friday, 12:00 p.m. to 5:00 p.m. Eastern Time

Spanish-speaking health information specialists are available.

**E-mail:** [ContactUs@AIDSinfo.nih.gov](mailto:ContactUs@AIDSinfo.nih.gov)

In December 2002, the U.S. Department of Health and Human Services (DHHS) AIDSinfo service was launched. The AIDSinfo project provides all of the services that were previously available from the AIDS Clinical Trials Information Service (ACTIS) and the HIV/AIDS Treatment Information Service (ATIS), as well as quick and easy access to wide-ranging Federal resources on HIV/AIDS clinical research, HIV treatment and prevention, and medical practice guidelines for health care providers and consumers. AIDSinfo includes databases that provide information about new and ongoing clinical trials that evaluate experimental drug treatments and candidate vaccines, including descriptions of clinical trials and the agents studied in those trials. The Web site also provides HIV vaccine information, supporting materials such as fact sheets, and links to published trial results and to other databases. The AIDSinfo Web site is user-friendly and easy to navigate. The site's many features include:

- Federally approved information on HIV/AIDS treatment and prevention guidelines

- Comprehensive database of Government- and industry-sponsored HIV/AIDS clinical trials
- Information about approved and experimental HIV/AIDS drugs and vaccines
- Education and Resource Center, offering links and other downloadable resources

AIDSinfo is sponsored by the NIH: Office of AIDS Research (OAR), National Institute of Allergy and Infectious Diseases (NIAID), and NLM; the Centers for Disease Control and Prevention; the Health Resources and Services Administration (HRSA); and the Centers for Medicare and Medicaid Services.

#### NIH Web Pages

The NIH continues to expand and improve its use of the Internet as an important medium for HIV/AIDS information dissemination efforts. NIH home pages, such as those for the NIH overall (<http://www.nih.gov>), OAR (<http://www.nih.gov/od/oar>), and all of the NIH Institutes and Centers (ICs) and Office of the Director (OD) offices, provide extensive HIV/AIDS research and programmatic information for the public, patients, health care providers, scientific investigators, press, and policymakers. Fact sheets, brochures, and news releases are also available. In particular, the NIAID Division of AIDS Web page (<http://www.niaid.nih.gov/daids/>) provides extensive and comprehensive information on HIV/AIDS treatment and prevention research, including HIV vaccines. NLM also has created a Web portal site specifically for HIV/AIDS-related information (<http://aids.nlm.nih.gov>). This site serves as an entry point to many of the HIV/AIDS-related resources available from the NIH and serves as a guide to selected resources worldwide. Another NLM site is MedlinePlus, which includes AIDS pages for consumers (<http://medlineplus.gov>).

#### **REPORTS OF MEETINGS, CONFERENCES, AND WORKSHOPS**

The NIH sponsors and supports a myriad of meetings, conferences, and workshops each year that bring together scientific experts to discuss critical scientific issues and develop recommendations or guidelines. The NIH makes the reports of these meetings available to the public in both written and electronic form through the various NIH Web sites.

**COMMUNITY  
OUTREACH  
PROGRAMS**

Providing accurate and up-to-date HIV/AIDS prevention and treatment information to communities at risk, including women and minorities, is a critical challenge. The NIH has a number of ongoing projects to address HIV/AIDS in minority and underserved communities.

Since FY 1994, the NIH, through NLM, has made annual awards of up to \$50,000 (or \$10,000 for simplified express awards) to enable community-based organizations (CBOs) and public and health science libraries to design their own programs for improving access to AIDS information for targeted groups, including people living with HIV/AIDS, their caregivers, communities at risk, and the general public. These awards support activities such as purchasing equipment and telecommunications services, implementing Internet access, training in the use of sophisticated information tools, and developing language- and culture-specific materials.

Training in the use of electronic HIV/AIDS resources, including the use of online databases, is included in NIH information dissemination programs. Curriculum-based AIDS information programs and modules are made available nationwide, including through the Historically Black Colleges and Universities, minority-serving educational institutions, as well as other groups of minority health professionals, such as the National Association for Equal Opportunity in Higher Education and the National Medical Association. Training is also carried out in conjunction with the DHHS Office of Minority Health Resource Center.

The NIAID-supported National HIV Vaccine Communications Steering Group has an ongoing campaign to increase awareness, educate, and stimulate dialogue within segments of the general public about HIV vaccine research. The Steering Group is comprised of community representatives, HIV vaccine advocates, and industry representatives and provides ongoing guidance to NIAID on how best to reach specific populations with messages about HIV vaccine research, including African Americans, Latinos, and men who have sex with men. The Steering Group's HIV Vaccine Communications Campaign has developed culturally appropriate materials, held conference workshops and forums, and sponsored meetings as part of its outreach efforts. The HIV Vaccine Communications Campaign also spearheads HIV Vaccine Awareness Day on May 18, an annual event to increase awareness of ongoing HIV vaccine research activities, to thank those who have volunteered for clinical trials, and to help foster interest in learning more about HIV vaccines.

## **Regional Information Dissemination Programs**

OAR sponsors a series of regional information dissemination programs to bring current research findings to community health professionals, particularly in minority communities, and to populations with the least access to information. This is accomplished through regional workshops, exhibit displays, and collaborative programs with other agencies and organizations.

### **Regional Workshops**

OAR also sponsors regional workshops targeted to Hispanic, Native American, Asian and Pacific Islanders, and African American communities. Events also have focused on issues relating to women, children, and injecting drug users. These 2-day events provide a forum for the presentation of research information. To ensure that the meetings are culturally appropriate and effective, they are planned in collaboration with scientists, researchers, community leaders, people living with HIV/AIDS, and care providers in the community.

### **Conferences**

OAR, in collaboration with HRSA, provides support to the National Minority AIDS Council (NMAC) for a series of conferences held in locations with the highest rates of HIV infection among minority populations in the United States. The purpose of these conferences is to help CBOs and leaders in case management and treatment meet the wide range of challenges in HIV treatment and adherence in communities of color. These conferences are unique opportunities for health care workers to receive critical research updates that contribute to the quality of care and life for infected individuals. This program has been in operation for 6 years.

### **Exhibit Displays**

OAR has developed two exhibits that are displayed at events in the United States and abroad. These exhibits offer insight into the HIV/AIDS research programs at the NIH.

*The NIH AIDS Research Program Exhibit* provides information on the HIV/AIDS research programs conducted and supported by the NIH. The exhibit provides publications, fact sheets, treatment guidelines, information about NIH Web sites, including AIDSinfo, and order forms for information from the ICs. The exhibit provides this critical information



about the NIH AIDS research program to scientists, health care workers, social workers, community-based workers, patients, and the public at domestic and international scientific and community-oriented events.

*The Children's Art Exhibit* was designed by OAR in collaboration with the Pediatric HIV Working Group of the National Cancer Institute (NCI). To help individuals better understand the challenges and triumphs of living with HIV and AIDS, this exhibit presents artwork created by children, adolescents, and young adults participating in the clinical trials of the Pediatric HIV Working Group of the NCI. The pictures in the exhibit are created by these young people, and in some cases their noninfected siblings, who are using this art to give form to their psychological experiences and tell the story of their journey of living with HIV and AIDS.

Many of the ICs also exhibit their own and other NIH programs and services at a wide variety of health and scientific meetings including those for scientists, clinicians, nurses, social workers, librarians, and specific population groups.

### **International Information Dissemination Programs**

Information and outreach programs for Latin America and the Caribbean have been a key priority for OAR for many years. OAR has collaborated for the past 13 years with the Office of Continuing Medical Education at the University of Puerto Rico and the AIDS Education and Training Centers of Puerto Rico on a series of meetings on key AIDS research topics. In 2000, in response to congressional appropriations language encouraging attention to AIDS in the U.S. Virgin Islands, OAR worked with Representative Donna Christian-Christensen to host a meeting on the island of St. Thomas. Plenary sessions were broadcast by satellite to other Caribbean islands, including the Bahamas, Jamaica, Trinidad and Tobago, and Barbados. Participants on each island viewed the morning plenary sessions and then conducted afternoon workshops to address topics of local interest. Most of the plenary and workshop sessions were captured on videotape and made available for broader viewing and posted on the OAR Web site.

In March 2004, OAR supported a conference entitled *A Multicultural Caribbean United Against HIV/AIDS*, which was sponsored by the University of Puerto Rico, the Caribbean Community, and the Caribbean Epidemiology Centre. Designed to complement the Caribbean conference held in 2000 that focused on the English-speaking Caribbean, this conference was held in Santo Domingo, Dominican Republic, and targeted 14 countries with

primary or significant populations that are Spanish-, French-, and Dutch-speaking. More than 1,800 scientists, researchers, health care providers, and individuals affected by HIV/AIDS attended this 3-day conference that provided information and a forum to develop a united response to the HIV/AIDS epidemic in the Caribbean.

OAR has expanded its information dissemination efforts to address critical needs in Africa. In 1999, a meeting on *Education and Training for Community-based Health Care Workers from Kenya, Tanzania, and Uganda* was held in Nairobi, Kenya, and a second meeting was held in Mombasa, Kenya.

In partnership with World Internet Resources for Education and Development, OAR provides resources to establish computer stations and medical information libraries in Community Health Information centers in Kenya. Training is provided to local individuals, and a local infrastructure is developed to allow communities to help each other access vital health care information and develop networks of care and support.

NLM has initiated a program with the Center for HIV Information (CHI) at the University of California, San Francisco (UCSF), to provide speedier access to reliable information about HIV and its treatment to health care providers in South Africa. This mirror server at the University of KwaZulu-Natal will be maintained by UCSF's CHI.

### **Collaboration with National/Community-based Organizations**

- OAR collaborates with a number of organizations addressing HIV/AIDS issues in racial and ethnic minority communities. OAR supports approximately 10 regional conferences each year focusing on treatment issues. These meetings are held in locations with the statistically highest HIV/AIDS rates in the United States.
- OAR has developed AIDS Information Kiosks that have been placed in strategic locations for access by at-risk populations, including in community college settings, at the University of Puerto Rico, through grassroots organizations working with youth, and with faith-based organizations. These computer kiosks allow directed searching through the Internet to learn more about HIV and AIDS. The home page and links created for this site direct the user through information on topics they query in English or Spanish.

- For the past several years, OAR has sponsored a scholarship program to provide computers to CBOs. These organizations use them for their own research and knowledge and also make them available to their clients. The computer is available to each successful awardee for 1 year and includes the necessary software, Internet service, telephone access, and training to develop an internal capability to enhance AIDS programs and services through this access. At the end of the year, the organizations have the option of purchasing the hardware and software licenses at reduced prices and assuming the other costs.



## SCIENTIFIC OBJECTIVES AND STRATEGIES

### OBJECTIVE - A:

**Support the effective dissemination, communication, and utilization of HIV/AIDS information to all constituent communities of the NIH, domestically and internationally.**

### STRATEGIES:

- Rapidly disseminate new research findings, including information on the potential implications for prevention, care, and treatment of HIV-infected individuals, using existing and innovative methods.
- Facilitate the development of HIV prevention and treatment guidelines based on the latest clinical research findings.
- Utilize computer and other information dissemination technology (including the Internet) to disseminate up-to-date HIV/AIDS information; information about HIV therapeutic, vaccine, and prevention trials; and information about HIV training programs.
- Expand access to and education about current state-of-the-art treatment and patient management guidelines, including information on clinical trials, using multiple technologies such as online access and voice access (AIDSinfo).
- Improve current techniques and develop and evaluate new techniques for the two-way communication of information to scientific and lay audiences, particularly to hard-to-reach populations, including information about clinical trials.
- Improve outreach and support access to HIV/AIDS information resources (including computers) by community groups, health care providers, and community-based HIV/AIDS service organizations, including those serving minority communities.
- Work with CBOs to develop and promote effective methods of information dissemination in target populations.
- Support dissemination of information, including to constituent communities, in culturally and linguistically appropriate ways.
- Develop and disseminate educational information to enhance understanding of HIV and basic and clinical research processes by health care providers, community-based HIV/AIDS service organizations, social service organizations, policymakers, and persons with HIV/AIDS.

- Develop and disseminate information resources about HIV vaccine clinical trials and the importance of potential HIV vaccines.
- Evaluate the effectiveness of communication efforts by appropriate means, including obtaining feedback from target audience members through such methods as usability testing of paper and computer interfaces (*see* [www.usability.gov](http://www.usability.gov)) and information dissemination intermediaries, such as journalists and health educators.
- Promote wide dissemination of the annual *NIH Plan for HIV-Related Research* and other HIV-related reports as they become available.
- Promote and enhance the exchange of scientific information and communication between public and private research enterprises, such as enhancing communication with the pharmaceutical industry concerning research on the development of therapeutics, vaccines, and microbicides, and working with industrial scientists to make information concerning basic science and HIV protein structures available to the general scientific community.
- Communicate and exchange information internationally on topics such as prevention and treatment, patient management guidelines, and research results that improve the care of HIV-infected individuals, including those in developing countries.
- Support the exchange of basic and applied research information at community, regional, national, and international conferences and workshops.
- Support the cross-collaborations of HIV/AIDS information providers to develop more integrated and comprehensive information dissemination approaches.
- Provide online access to presentation materials, including full text of abstracts and other information (e.g., slides, graphics, plenary presentations) from scientific meetings.
- Collect, archive, and promote use of existing data from NIH-supported basic and applied research for secondary data analysis, including rapid development of public use data sets that can be used for secondary data analysis in NIH-supported studies, especially baseline survey and HIV/STD (sexually transmitted disease) incidence data.

- Widely disseminate information concerning specimen repositories, including existing repositories, specimens available, and relevant information concerning cohorts, contact information, and the process for obtaining access to samples.

**OBJECTIVE - B:**

**Support research to identify existing gaps in communication approaches, identify and evaluate existing strategies, and develop and test new and innovative communication strategies that will improve access to and use of state-of-the-art HIV information by all relevant target audiences, domestically and internationally.**

**STRATEGIES:**

- Assess the information needs and resources used by various audiences, including biomedical and behavioral research communities, health care providers, service providers, persons living with HIV and their advocates, at-risk populations, scientific and lay media, and the general public.
- Identify obstacles to information dissemination and develop, test, and evaluate possible ways to overcome these obstacles.
- Develop, test, and evaluate innovative strategies for effectively reaching specific audiences (e.g., minority communities, adolescents, drug users, other hard-to-reach populations, and health care providers) with relevant HIV information.
- Investigate how and under what circumstances different communication and dissemination strategies influence the adoption of scientifically based HIV behavior-change interventions and clinical practices in specific audiences.
- Promote use of new technologies and evaluate their effectiveness for disseminating basic and clinical research findings.
- Work to reduce communication gaps between academic researchers and treatment providers so that research results are more effectively disseminated to providers and that research agendas reflect the needs of practicing clinicians.



**OBJECTIVE - C:**

**Develop, implement, and evaluate methods of coordination and collaboration on HIV/AIDS communications activities among NIH ICs and with other Federal and non-Federal groups.**

**STRATEGIES:**

- Build and enhance partnerships among CBOs and basic, clinical, and behavioral researchers to encourage exchange of information and experience.
- Promote and foster information dissemination regarding research and programmatic efforts across the ICs, among U.S. Government agencies, and with international partners.
- Promote collaboration among all ICs in providing information about their HIV/AIDS clinical trials to AIDSinfo and ClinicalTrials.gov.
- Expand the development of HIV/AIDS resources on the Internet to facilitate national and international research collaboration and data sharing.
- Continue collaborations with the Joint United Nations Programme on HIV/AIDS, the Pan American Health Organization, and other international AIDS agencies or societies on information/communications efforts, including information about international clinical trials.
- Collaborate with public and health sciences libraries, health care providers, AIDS education and training centers, and community-based HIV/AIDS service organizations to facilitate access to needed information.
- Expand collaboration to include academic, medical, and other communities, as appropriate, in the dissemination of NIH HIV-related reports.

